

NIH Strategic Research Plan to Reduce and Ultimately Eliminate Health Disparities

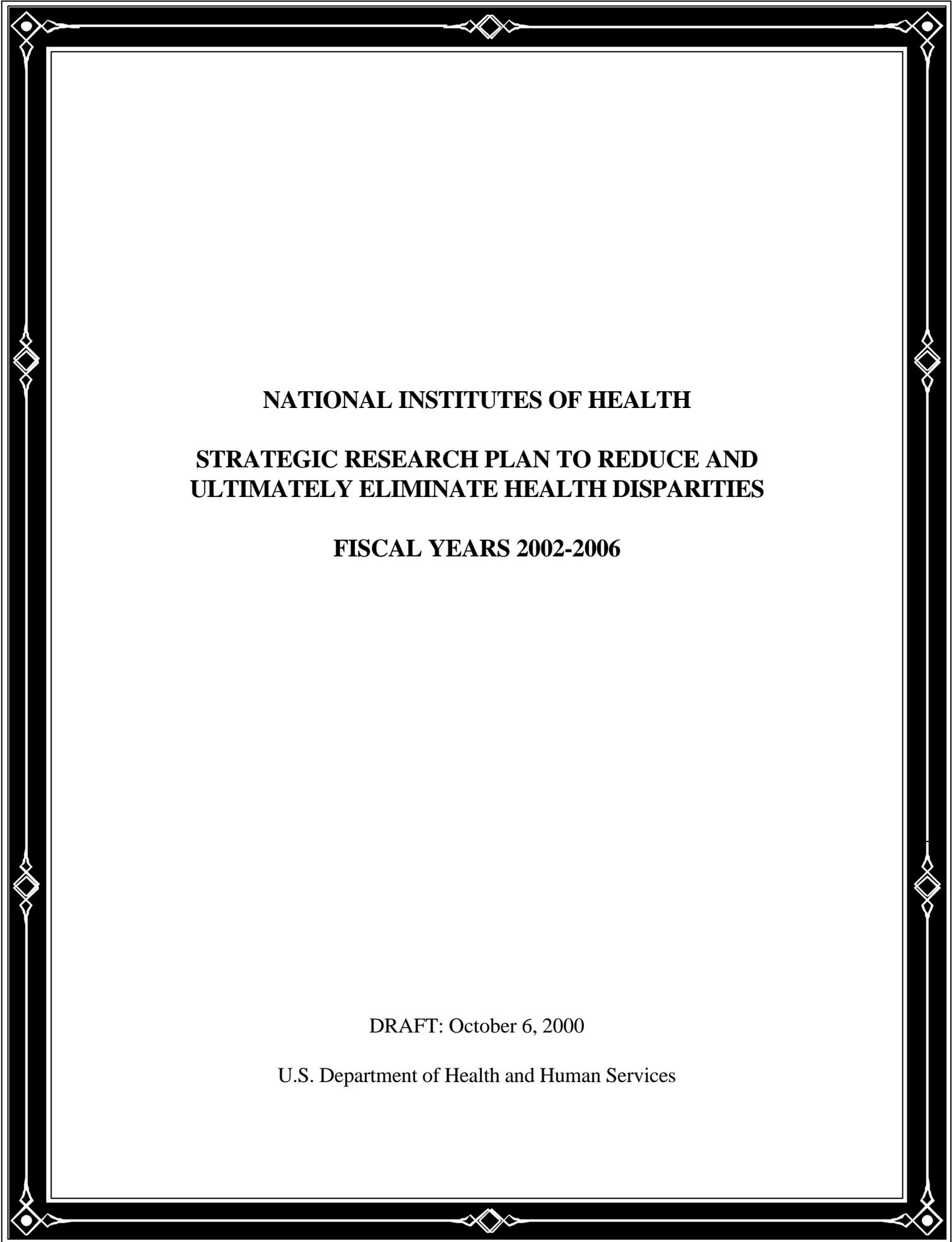
The draft Trans-NIH Strategic Research Plan on Health Disparities has been developed by a Trans-NIH Working Group which consists of each NIH Institute and Center Director. The Working Group is co-chaired by the NIH Acting Deputy Director Dr. Yvonne Maddox and the NIAID Director Dr. Anthony Fauci. Ex-officio members of the Working Group are Dr. Ruth Kirschstein, the NIH Principal Deputy Director and Dr. John Ruffin, the NIH Associate Director for Minority Research.

The Plan was developed through an open process with substantial public input, particularly from representatives of groups who disproportionately experience disparities in health. It describes the activities underway and planned to bring the full strength of NIH's research and training programs to bear on the challenge of eliminating domestic health disparities, increasing participation by minorities in clinical research, and increasing the number of minority clinical and basic medical scientists who are essential to the success of our efforts.

NIH welcomes your comments and suggestions on the draft Plan.
The comment period has been extended to February 23, 2001.

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NATIONAL INSTITUTES OF HEALTH

**STRATEGIC RESEARCH PLAN TO REDUCE AND
ULTIMATELY ELIMINATE HEALTH DISPARITIES**

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U.S. Department of Health and Human Services

NIH Strategic Research Plan to Reduce and Ultimately Eliminate Health Disparities

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Foreword

Despite notable improvements in the overall health of the Nation in the last two decades, there continue to be striking disparities in the burden of illness and death experienced by African Americans, Hispanics, Native Americans, Alaska Natives, Asians, and Pacific Islanders. Overcoming such persistent and perplexing health disparities, and promoting health for all Americans, particularly those who have suffered most, ranks as one of our Nation's foremost challenges.

The mission of the National Institutes of Health (NIH) is to improve the Nation's health by uncovering new knowledge about the prevention, detection, diagnosis, and treatment of disease and disability. Our mission is, thus, central to the expanding national efforts to address differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States. To this end, the NIH developed this five-year *NIH Strategic Research Plan to Reduce and Ultimately Eliminate Health Disparities*. This strategic plan sets forth NIH's goals for reducing and, ultimately, eliminating health disparities among racial and ethnic minorities and describes some of the many initiatives that will be expanded or created to meet these goals.

All of us who have been privileged to participate in this age of scientific discovery have a responsibility to ensure that the new knowledge generated in our laboratories and our clinics benefits all of our citizens and all of our communities. Our aim at the NIH is to promote the development and transfer of research-based information from biomedical, behavioral, and social sciences for use by health professionals, communities, and others in working toward the elimination of health disparities.

The development of this *NIH Strategic Research Plan to Reduce and Ultimately Eliminate Health Disparities* serves as a public reaffirmation of NIH's commitment to bringing the full strength of its research and training programs to bear on the goal of reducing, and ultimately eliminating, domestic health disparities. Each Institute and Center Director at the NIH has personally pledged his or her support for this endeavor.

While the diversity of the American population remains one of our Nation's greatest assets, the profound discrepancies in health status described here represents a challenge—to better understand these disparities, and to reduce and ultimately eliminate them.

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NIH Strategic Research Plan to Reduce and Ultimately Eliminate Health Disparities

Executive Summary

While the overall health of the Nation has improved over the last two decades, there continue to be striking disparities in the burden of illness and death experienced by African Americans, Hispanics, Native Americans, Alaska Natives, Asians, and Pacific Islanders. The most striking disparities include shorter life expectancy as well as higher rates of cardiovascular disease, cancer, infant mortality, birth defects, asthma, diabetes, stroke, sexually transmitted diseases, and mental illness. These disparities are believed to be the result of the complex interaction among biological factors, the environment, and specific health behaviors. Inequalities in income and education also appear to underlie many health disparities in the United States. Disparities in income and education levels are associated with differences in the occurrence of illness and death, including heart disease, diabetes, obesity, elevated blood lead level, and low birth weight.

It is an imperative that the nation make a concerted effort to reduce health disparities. To this end, the National Institutes of Health (NIH) has a unique and central role in this endeavor. By supporting and conducting medical research, the NIH seeks new knowledge about disease and disability—new knowledge that has and will continue to lead to innovative diagnostics, treatments, and preventive strategies to reduce, and even eliminate, health disparities.

A comprehensive national effort to prevent disease, promote health, and deliver appropriate care to racial and ethnic minorities—all of which are necessary to achieving the goal of reducing, and even eliminating, these disparities—cannot, however, be accomplished by NIH-supported research alone. Federal, State and local governments each have their roles to play, as do private sector healthcare providers and payers, as well as patients and their families. In order to make substantial inroads in the reduction of health disparities, the nation must, for example, monitor the health status of different populations; use the information gained from research to change the delivery of services; and ensure the distribution of these services across all segments of our population.

Recognizing the importance of sustaining and enhancing its commitment to improve minority health, the NIH will focus its initial efforts on specific racial/ethnic minority populations, including African Americans, Asians, Pacific Islanders, Hispanics, Native Americans, and Alaska Natives. Each Institute and Center and three program offices in the Office of the Director of the NIH has developed its own mission-specific strategic plan that sets forth in greater detail ongoing and planned efforts to reduce health disparities among these populations. These plans can be found on the NIH Home Page at:

<http://healthdisparities.nih.gov/working/institutes.html>

The NIH has also developed this five-year *NIH Strategic Research Plan to Reduce and Ultimately Eliminate Health Disparities*. This plan sets forth NIH's objectives for reducing and, ultimately, eliminating health disparities among racial and ethnic minorities and describes some of the many initiatives that will be expanded or created to meet these goals. The plan is focused on three major areas: research; research infrastructure; and public information and community outreach.

Research to advance our understanding of the development and progression of diseases and disabilities that contribute to health disparities in minority populations is central to this effort. For example, the NIH will strengthen and expand research on the epidemiology and risk factors related to a variety of diseases and conditions that disproportionately affect minority populations, including infant mortality, stroke, cardiovascular disease, hepatitis C, cancer, drug abuse and addiction, sexually transmitted diseases, oral diseases and disorders, and glaucoma, among others. Research efforts will also be directed to the role of the environment and socioeconomic status in health disparities. Our efforts will also include studies on biologic variations in the etiology and treatment of diseases, such as diabetes, hypertension, alcoholism, and lupus. Efforts to develop new or improved approaches for detecting or diagnosing the onset or progression of diseases and disabilities that contribute to health disparities in minority populations will involve, for example, research on prostate cancer and mental and language disorders. New or improved approaches for preventing or delaying the onset or progression of diseases and disabilities in minority populations will be explored as they relate to diseases such as diabetes, obesity, dental caries, asthma, and HIV vaccine development, among others. Finally, new or improved treatments will, for example, be directed at mental illness, cancer survivorship, end of life/palliative care, tuberculosis, diet and hypertension, and alternative medicine.

Research infrastructure objectives will include efforts to support research training and career development such as support for doctoral Dissertation Research and Travel Awards, Minority Access to Research Careers (MARC) awards, Clinical Research Training, Short-term Training for Minority Students, the Minority Undergraduate Biomedical Education Program, and the Minority Medical School Research Program, among others. Our infrastructure initiatives will also include institutional support for extramural and intramural resources such as strengthening science curricula, enhancing capacity of minority and underserved institutions to participate in communications and networking technologies, training minority clinical trial investigators, recruiting minorities into clinical trials, and expanding Institutional Development Awards, and increasing minority representation in peer review.

In the arena of public information and community outreach, our objectives include plans to develop research-based information resources, such as the NIH Hispanic Communications Initiative, internet-based information resources, the Health Information National Trends Survey, and information clearinghouses, among others. Efforts to communicate research-based information to increase public awareness are exemplified in ongoing and new programs, such as the National Diabetes Education Program, Environmental Justice Partnerships for Communications, programs on public input/policy on genetic research, the Asian and Pacific Islander Project, and Science for the Lay Public. Efforts to transfer knowledge to health care providers will include the Urban Clinical Center and Tuberculosis Trials, and the National Kidney Diseases Education Program, and the National Eye Health Education Program, among others.

All of these many initiatives cut across a variety of areas representing myriad diseases, disabilities, and organizational boundaries. They represent a trans-agency commitment to exploring and solving many of the health disparities problems our citizens and our Nation face. Much needs to be done, but we are confident that the medical research community working with, and informed by, the public, patients, health care providers, policymakers, and others will continue to develop new knowledge that leads to improvements in the prevention, diagnosis, and treatment of diseases and disabilities that contribute to health disparities among racial and ethnic minorities.

Introduction

One of the central features of contemporary America is that it is increasingly diverse. This diversity remains one of our Nation's greatest assets. However, there is compelling evidence that U.S. minority populations suffer from increasing differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions. These health disparities include shorter overall life expectancy, higher rates of cardiovascular disease, cancer, infant mortality, birth defects, asthma, diabetes, stroke, sexually transmitted diseases, oral diseases and disorders, and mental disorders, among others. Contributing factors include reduced access to health care, increased risk of disease and disability due to occupation or exposure, and increased risk of illness due to underlying biological, socioeconomic, ethnic, or familial factors; cultural values, and education.

As part of our mission to uncover new knowledge that will lead to better health for everyone, the National Institutes of Health (NIH) supports research to understand the epidemiology of diseases, to distinguish their causes, and to develop innovative diagnostics, treatments, and preventive strategies to reduce, and ultimately to eliminate, health disparities. We have defined health disparities as: differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States. Research on health disparities related to socioeconomic status is also encompassed in the definition. With the issuance of this Strategic Research Plan, NIH began using a different definition of health disparities than it had previously. The change in definition has resulted in a change in the funding that NIH is reporting as focused on health disparities.

The NIH is focusing its initial attention on the health status, including socioeconomic factors, of

specific racial and ethnic minority populations: African Americans, Asians, Pacific Islanders, Hispanics, Native Americans, and Alaska Natives. The scope of the problem of health disparities among minorities, the specific objectives for solving the problem, and the means for advancing those objectives are the substance of this strategic plan.

The initiatives described here represent but a subset of the broad range of activities that the NIH will undertake to eliminate health disparities. Each Institute and Center and three program offices in the Office of the Director of the NIH has developed its own mission-specific strategic plan that sets forth in greater detail ongoing and planned efforts to reduce health disparities among racial and ethnic minorities. These plans can be found on the NIH Home Page at: <http://www.nih.gov>.

Scope of the Problem

Nationally, racial and ethnic minorities are projected to grow from 28 percent of the U.S. population in 1998 to nearly 40 percent in 2030. A strengthened commitment to research that seeks to better understand health disparities and to develop new diagnostic, treatment, and prevention strategies to overcome them is a sound investment for the health and well-being of our citizens and our Nation.

Although observations and anecdotes can provide us with clues about health disparities, it is only through rigorous population and epidemiologic research that the health care community can discern where disparities exist, define the scope of the problem, and then identify and evaluate new approaches to reduce, and even eliminate, them. What follows are selected data that illustrate the magnitude and breadth of health disparities among various racial and ethnic subpopulations. These data provide a landscape

for the task ahead. The challenge for the NIH, and the Nation, is to do our best to identify, better understand, diagnose, treat, and even prevent these disparities.

Infant Mortality. Infant mortality is an important measure of a nation's health and a worldwide indicator of health status. Despite a 16 percent overall decline in the rate of infant mortality in the U.S. over the last decade, the infant mortality rate remains twice as high among African Americans as compared to Caucasians, even when controlling for socioeconomic factors. Native American and Alaska Native infants also have a death rate almost double that of Caucasians.

Maternal Mortality and Morbidity. The disparities in U.S. maternal mortality and morbidity are also great. Maternal mortality rates in the U.S. have decreased dramatically since the 1950s. However, as compared to Caucasians, the mortality rate remains four times higher among African American mothers and 1.6 times higher for other racial groups. These deaths, which have a profound effect on the family, are often preventable. Many factors influence maternal morbidity in minority populations. For example, African American women develop uterine fibroids up to two to three times more frequently than Caucasian women. Such fibroids are also often overlooked as a source of lost productivity and significant health care costs.

Poverty and Child Health. In 1996, African American and Hispanic children were four times more likely to live in poverty than Caucasian children. These disadvantaged children experience a disproportionate array of health problems, including high rates of low birth weight, contagious diseases, obesity, exposure to hazardous substances, and childhood injury and death. They are also at greater risk for developmental and learning delays, as well as social, emotional, and behavioral problems.

Asthma. Asthma, which is one of the major causes of illness and disability, increased in prevalence by 72 percent from 1982 to 1994 among young people under age 18. Despite the fact that asthma is only slightly more prevalent in African American children than in Caucasian children, African American children experience more severe disability and more frequent hospitalization.

Fetal Alcohol Syndrome (FAS). FAS is a preventable condition which is six times more prevalent among African Americans than Caucasians. Some Native American tribes have 33 times the incidence of FAS found in Caucasians. This often devastating syndrome can lead to life-long neurological, behavioral, and cognitive deficits that prevent normal learning and socialization. It can also be associated with growth deficiency, organ abnormalities, and other physical malformations.

Heart Disease. Despite impressive progress in reducing cardiovascular mortality over the past several decades, there still exists a disproportionate burden of death and disability from cardiovascular disease in minority and low-income populations. For example, the prevalence of coronary heart disease in African Americans has increased steadily since the early 1970s, with coronary heart disease mortality 40 percent higher for African Americans than Caucasians. Similarly, fewer African Americans survive severe cardiomyopathy as compared to Caucasians—a difference which is attributed to both biological and socioeconomic factors.

Stroke. Stroke is the third leading cause of death in the U.S., killing approximately 150,000 Americans every year. The incidence of stroke is disproportionately high in African Americans, where the mortality rate is nearly 80 percent higher than in Caucasians.

Sickle Cell Anemia. This inherited and deadly disease of the blood is most common among

those whose ancestors come from Africa, the Middle East, the Mediterranean basin, and India. In fact, one in 12 African Americans carries the sickle cell trait. In the U.S., it primarily affects African Americans, about 72,000 of whom have the disease. Sickle cell disease has serious consequences. For example, it is the most important cause of stroke in African American children.

Cancer. Cancer is the second most common cause of mortality in the U.S. In the year 2000, about 1.2 million cases are expected to be diagnosed, with 552,200 Americans dying from the disease. Many minority groups suffer disproportionately from cancer, and disparities exist in both mortality and incidence rates. For example, African Americans have both a higher overall incidence and death rate than any other racial or ethnic group. The death rate from stomach cancer is substantially higher among Asian and Pacific Islanders, including Native Hawaiians, than among other populations. Vietnamese women in the U.S. have a cervical cancer incidence rate that is five times greater than Caucasian women, and African American and Hispanic women have higher cervical cancer death rates than the overall U.S. population.

Mental Health. Disease burden associated with mental disorders falls disproportionately on ethnic minority populations. Native American and Alaska Natives not only suffer disproportionately from depression, but this population also experiences higher rates of suicide. In African American youth aged 15-19, suicide rates have increased 105 percent since 1980—a rate of increase that far exceeds the increase in rates for Caucasian youth.

Drug Use. While drug use is generally no higher among minority groups than among the general population, African Americans, Native Americans, Alaska Natives, and Hispanics are more likely than Caucasians to die from drug-induced death. African American and Hispanic injecting drug users also appear to be more likely

than their Caucasian counterparts to contract AIDS.

Epilepsy. There is new evidence that the incidence of epilepsy is 50 percent higher in African American than Caucasian populations in some communities. This disparity has been attributed to socioeconomic differences and other factors including nutrition, exposure to violence, reduced health infrastructure, and altered access to medical care.

Type 2 Diabetes. Diabetes affects nearly 16 million Americans and leads to more than 300,000 deaths annually. It is also the leading cause of end stage kidney disease, peripheral neuropathy, adult blindness, and amputation. More than 90 percent of those affected have type 2 diabetes, which is disproportionately manifested in minority groups. The prevalence of diabetes in African Americans is nearly 70 percent higher than in Caucasians. Native Americans, Hispanics, African Americans, and some Asian Americans and Pacific Islanders, including Japanese Americans, Samoans, and Native Hawaiians, are at particularly high risk for development of type 2 diabetes. Most strikingly, diabetes prevalence rates among American Indians are two to five times those of Caucasians, with the Pima tribe of Arizona experiencing one of the highest rates of diabetes in the world.

End Stage Renal Disease. A major public health problem in the U.S. is end-stage renal disease. There are striking racial and ethnic differences in the incidence and prevalence of this disease. In 1997, the incidence rates were 218 per million population in Caucasians, as compared to 873 in African Americans, and 586 in Native Americans and Alaska Natives.

Liver Disease. Cirrhosis of the liver is responsible for approximately 25,000 deaths in the U.S., at least half of which are attributable to alcohol. In 1992, the death rate in alcohol-related cirrhosis among African American males was 73.8 percent greater than that among Caucasian

males. Alcoholic liver disease and hepatitis C are also leading causes of end-stage liver disease in the U.S. The hepatitis C virus is a blood-borne agent that infects cells of the liver and affects 3.9 million Americans. African Americans are infected with hepatitis C virus at twice the rate of non-minority populations and tend to be less responsive to therapy.

HIV and AIDS. HIV and AIDS continue to affect minorities disproportionately. Of all U.S. cases reported to the Centers for Disease Control and Prevention (CDC) in 1998, 45 percent were among African Americans, 33 percent among Caucasians, 20 percent among Hispanics, and less than 1 percent among Asians and Pacific Islanders and Native Americans and Alaska Natives. The rate of new AIDS cases reported in 1998 per 100,000 population was 81.9 among African Americans, 34.7 among Hispanics, 8.4 among Caucasians, 9.4 among Native Americans and Alaska Natives, and 4.1 among Asians and Pacific Islanders. HIV incidence is growing at a greater rate in women than in men, particularly among minority women. The proportion of new AIDS cases among women more than tripled from 1985 to 1998, from 7 percent to 23 percent. In the U.S., by the end of 1998, more than 77 percent of women infected with the AIDS virus were from minority groups, with 57 percent African American and 20 percent Hispanic.

Sexually Transmitted Diseases. The current sexually transmitted disease epidemic in the U.S. disproportionately affects minorities. For example, in 1997, the rate of gonorrhea remained 31 times greater among African Americans than Caucasians, and 3 times greater for Hispanics. This disparity is particularly significant in light of recent studies that indicate that sexually transmitted diseases such as chlamydia, gonorrhea, trichomoniasis, genital herpes, syphilis, and chancroid increase the risk of HIV transmission by at least three- to five-fold.

Tuberculosis. In the U.S., tuberculosis has re-emerged as a serious public health problem, and

one that affects minorities disproportionately. For example, in 1998, 75 percent of active tuberculosis cases were reported in racial and ethnic minorities due largely to a combination of problems related to urban poverty, overcrowded living conditions, HIV infection, and inadequate treatment and/or compliance with tuberculosis therapy. Although constituting only 11 percent of the total population in 1996, Hispanics accounted for 20 percent of the new cases of tuberculosis. New cases of tuberculosis are also higher in Asians and Pacific Islanders living in the U.S. than in Caucasians.

Oral Health. Most oral diseases and conditions, including oral and pharyngeal cancer and cleft lip/palate, dental caries, periodontal diseases are borne by racial and ethnic minorities. Oral and pharyngeal cancers are the fourth most common cancer in African American males and these cancers are less likely to be diagnosed at localized stages of disease compared with Caucasians. Untreated dental caries and periodontal disease are twice as prevalent in African American and Hispanic adolescents and adults as compared to Caucasians in these age groups.

Vision Disorders. Primary open-angle glaucoma is an insidious progressive neuropathy that, if left untreated, leads to irreversible blindness. It is estimated that as many as 3 million Americans have the disease and as many as 120,000 are blind. Glaucoma is the number one cause of blindness in African Americans. Rates of blindness due to primary open-angle glaucoma in African Americans are nearly six times higher than the rates for the Caucasian population, reflecting not only an increased rate of disease, but also more severe disease.

Hearing Disorders. Otitis media, or middle ear infection, is the most common cause for acute care visits by children to physicians, costing several billion dollars annually in the U.S. Native American infants have one of the highest rates of otitis media in our country—an infection which can

lead to serious disabilities, such as permanent hearing deficits, reading disorders, and language delays, as well as increased risk of more serious infection such as meningitis.

Smoking and Tobacco Usage. According to the Global Burden of Disease Study, commissioned by the World Bank, smoking-related illnesses will be one of the major contributors to the premature death and disability worldwide in the coming decades. Disparities in tobacco use exist among certain racial and ethnic populations. For example, Native Americans and Alaska Natives are more likely to smoke than other racial and ethnic groups, with considerable variations in percentages by Tribe.

Osteoarthritis. African Americans have a higher risk than Caucasians of both bilateral knee osteoarthritis and hip osteoarthritis. In African Americans, obesity is a more important risk factor for bilateral knee osteoarthritis than in Caucasians.

Lupus. Lupus is estimated to affect 239,000 Americans. The condition often starts between the ages of 15 and 44, and can affect many parts of the body, including the skin, kidneys, heart, lungs, blood vessels, and brain. Lupus is three times more common in African American women and the mortality rate in this population is three times higher than that of Caucasian women. Lupus is also more common in women of Hispanic, Asian, and Native American descent than in Caucasians.

Scleroderma. The hallmark of this autoimmune disorder is widespread hardening of the skin, which can involve tissues in the lungs, heart, kidneys, intestinal tract, muscles, and joints. In severe cases, the disorder can be fatal. This disorder is particularly prevalent in Native American women. Although the cause is unknown, researchers believe both environmental and biologic factors play a role in disease development.

Federal Efforts to Address Health Disparities

Because of the profound health disparities that exist between and among different racial and ethnic groups, the Federal Government is engaged in a number of key initiatives aimed at addressing these disparities.

One America in the 21st Century: The President's Initiative on Race seeks to overcome racial divisions in our society. One of the initiatives in this effort is to reduce health disparities among racial and ethnic minorities by, for example, improving the health-care infrastructure and removing obstacles to the delivery of, and access to, health care among these populations.

Complementing this is *Healthy People 2010*, a national health promotion and disease prevention initiative which sets forth the Nation's health objectives for the 21st century, including a major goal of eliminating health disparities among different segments of the population. These include differences that occur by gender, race or ethnicity, education or income, disability, living in rural localities, or sexual orientation. Like its predecessor initiatives, *Healthy People 2010* was developed through a broad consultation process, built upon the best scientific information, and designed to measure progress over time. NIH Institutes and Centers are the lead or co-lead agencies for 12 of the 28 focus areas of *Healthy People 2010*.

The Department of Health and Human Services (DHHS) also launched an *Initiative to Eliminate Racial and Ethnic Disparities in Health* to improve prevention of disease, promotion of health, and delivery of care to these populations. The six areas DHHS chose for particular attention are listed below.

HHS Initiative to Eliminate Racial and Ethnic Disparities in Health

1. Infant Mortality
2. Cancer Screening & Management
3. Cardiovascular Disease
4. Diabetes
5. HIV Infection/AIDS
6. Immunization

NIH's Role in the National Effort to Reduce and Ultimately Eliminate Health Disparities

Many Federal Departments and Agencies play an important role in the national effort to eliminate health disparities among racial and ethnic minorities. These roles range from monitoring health status among different population groups; supporting and conducting research to investigate the basis for these differences and develop new or improved prevention strategies, diagnostics, and treatments; using the information gained from research to develop evidence-based guidance for preventive and treatment services; and providing support for the provision of these services. While NIH funded research has and continues to yield information that is important to addressing the complex and vexing problem of disparities in health status among racial and ethnic minorities, it is but a part of the aggregate effort to prevent disease, promote health, and deliver appropriate care to racial and ethnic minorities—all of which are necessary to achieving the goal of eliminating these disparities.

NIH occupies a unique place in the Federal effort to eliminate health disparities among racial and ethnic minorities. NIH works with the public, health care providers, scientists, and policymakers to identify the researchable issues; develops the research plan to address these issues; and supports and conducts a broad range of studies in this area.

These include epidemiology; biological, behavioral, and social science research; as well as health services research. In addition, NIH provides support for the infrastructure that underpins the research enterprise, such as training and instrumentation. The NIH carries out public information and community outreach to communicate research findings to individuals, organizations, and other entities who can put the results into practice.

The NIH also continues its commitment to the inclusion of women and racial and ethnic minority groups and their subpopulations in research, consistent with the NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research. Because the ultimate aim of research is to provide scientific evidence which informs health policy or standards of care, it is imperative to determine whether the intervention or therapy being studied affects women or men or members of minority groups and their subpopulations differently. To this end, the NIH guidelines help to ensure that NIH-supported biomedical and behavioral research involving human subjects is carried out in a manner sufficient to elicit relevant information about individuals of both genders and diverse racial and ethnic groups and, in the case of clinical trials, to examine differential effects on such groups. NIH will continue to ensure that all clinical trials that are funded by the agency adhere to the NIH Guidelines.

The NIH Approach to Addressing Health Disparities

The NIH has long been committed to addressing and reducing health disparities. The NIH is comprised of twenty-five Institutes and Centers (ICs), along with other program offices in the Office of the Director (OD). In an effort to ensure that all of our citizens benefit from the advances in medical research, the

Acting Director of NIH established a trans-NIH Working Group on Health Disparities that includes the Institute and Center (IC) Directors, the Director of the Office of AIDS Research (OAR); and the Associate Directors of the Office of Behavioral and Social Sciences Research (OBSSR); the Office of Disease Prevention (ODP); and the Office of Research on Women's Health (ORWH) as its members. Each IC and the OBSSR, ODP, and ORWH were charged with developing a mission-specific strategic plan that sets forth in greater detail ongoing and future efforts to reduce health disparities among racial and ethnic minorities. These plans were prepared in consultation with the public, professional and patient advocacy groups, Institute Advisory Councils, and the scientific community; they can be found on the Institute and Office home pages that are listed in the Appendix.

The trans-NIH Working Group on Health Disparities was also charged with developing a trans-NIH Plan to Address Health Disparities, which would be cleared by the Acting Director, NIH, and the Associate Director, Office of Research on Minority Health (ORMH). This Plan draws on health disparities plans of the NIH Institutes, Centers, and relevant OD offices. The Plan is not a compilation of all the activities of all of the relevant NIH entities. It does, however, aggregate numerous programs and activities conducted across the agency and provides the reader with an understanding of the cross-cutting nature of disease and scientific discovery. The Plan is focused on three major areas: 1) Research; 2) Research Infrastructure; and 3) Public Information and Community Outreach.

With regard to research, the Plan outlines our ongoing and future efforts to support and conduct research that is multifaceted, taking into account all possible explanations for why health disparities might exist, from the molecular to the population levels. Expanded and new research efforts will focus on understanding the development and progression of disease that contributes to health disparities, and the development of new or

improved approaches for preventing, detecting, diagnosing, or treating disease and disability.

Success in this critical endeavor will require a robust and stable research infrastructure. This infrastructure must include training programs across the country, at the NIH campus in Bethesda, Maryland, and at other NIH locations in the U.S., as well as programs to enhance research capacity at minority institutions. It must also include a peer review system prepared to evaluate the quality of grant applications relevant to health disparities.

Communicating the scientific and health information gained from research into health disparities is also paramount. These efforts extend beyond dissemination of the results of research to other scientists. It must include the transmission of all information that may improve the health of minorities to the general public, patients, advocacy groups, health care providers, media, and policymakers. This includes comprehensive and aggressive outreach to those groups whom the research is intended to help and their health care providers. And these messages must be tailored to the communities at highest risk for the adverse consequences of the health disparity in question. While NIH's efforts to date have been strong, we need to further strengthen and expand our efforts to produce health information that is culturally appropriate and ensure that it is disseminated to the appropriate communities. Finally, it is critically important to develop methods to assess the effectiveness of these communication efforts.

NIH has identified specific objectives in each of these areas: research; infrastructure; and public information and community outreach (see Table 1). Examples of ongoing and proposed initiatives to achieve these objectives are described below. In addition, as noted previously, further information about each of the initiatives can be found on the web sites listed in the Appendix.

Table 1
**NIH Strategic Research Plan to Reduce and Ultimately Eliminate
Health Disparities**

**GOAL: TO REDUCE AND ULTIMATELY ELIMINATE HEALTH DISPARITIES
AMONG RACIAL AND ETHNIC MINORITIES.**

Research Objectives

1. Advance understanding of the development and progression of diseases and disabilities that contribute to health disparities in minority populations.
2. Develop new or improved approaches for detecting or diagnosing the onset or progression of diseases and disabilities that contribute to health disparities in minority populations.
3. Develop new or improved approaches for preventing or delaying the onset or progression of diseases and disabilities that contribute to health disparities in minority populations.
4. Develop new or improved approaches for treating diseases and disabilities that contribute to health disparities in minority populations.

Research Infrastructure Objectives

1. Support research training and career development
2. Provide support for institutional resources (extramural and intramural).

Public Information and Community Outreach

1. Develop research-based information resources
2. Communicate research-based information to increase public awareness
3. Transfer knowledge to health care providers

Research

A variety of studies conducted at the population level have yielded important information about gender, racial, and ethnic differences in disease morbidity and mortality. These studies have also raised intriguing questions about the relative roles of biology, behavior, environment, and socioeconomic status in human health and disease. For example, there is a striking and well-documented relationship between socioeconomic status, health, and longevity. However, while economic resources are an important determinant of access to quality health care, they are insufficient to explain individual health outcomes. Factors such as early childhood experiences, the cumulative effects of prolonged exposure to stress, and/or biological differences in, and response to, disease and risk may account for some observed health differentials.

Thus, we need to understand how biological, behavioral, and environmental factors interact to affect human health in different populations. With this in mind, the NIH has identified four research objectives which seek to understand the causes of health disparities and to promote development of preventions, diagnostics, and treatments to reduce or eliminate them (see Table 1).

The following sections provide selected examples of the variety of ongoing and new research studies that NIH will support as part of its strategic plan for understanding and reducing health disparities among ethnic and racial minorities. The ultimate goal of these research efforts is to develop improved means for prevention, diagnosis, and treatment of diseases and disabilities that disproportionately affect specific populations. These activities are summarized in Table 2.

Selected Examples of Research Initiatives by Objective

1. Advance understanding of the development and progression of diseases and disabilities that contribute to health disparities in minority populations.

Research on normal biological processes and how they malfunction in disease and disability provides the foundation for disease-oriented investigations that ultimately lead to new methods for diagnosing, treating, and preventing disease and disability in different populations. This requires an understanding of how living systems operate at both a “micro” level—the structure and function of proteins, nucleic acids (DNA and RNA), carbohydrates, and fats—and at more “macro” levels, such as cells, tissues, organs, systems, organisms, and communities. As important, we need to understand the effects of disease, genetic alterations, and environment at these different levels in different populations and their consequences for human health. This knowledge will be important for clarifying why rates and outcomes of illness differ among population groups.

To advance understanding of the development and progression of diseases that contribute to health disparities, a variety of approaches must be pursued, including studies of epidemiology and risk factors among diverse populations; the effects of environment and socioeconomic status on disease and health outcomes; differences in the initiation and progression of disease and disability; and the role of genetic variation in the causes and course of disease and disability.

Table 2
Selected Examples of NIH Research Initiatives to
Reduce and Ultimately Eliminate Health Disparities

1. *Advance understanding of the development and progression of diseases and disabilities that contribute to health disparities in minority populations.*

Epidemiology and Risk Factors

Stroke
 Cardiovascular Disease
 Hepatitis C
 Cancer Surveillance
 Prostate Cancer
 Drug Abuse and Addiction
 Sexually Transmitted Diseases
 Oral Health
 Osteoarthritis
 Glaucoma
 Youth Violence
 Alternative Medicine

Environment and Socioeconomic Status

Biomarkers for Diseases
 Centers for Health Disparity Research
 Cognition

Mechanisms of Disease

Perinatal Research
 Injury
 Stress
 Scleroderma

Genetic Variations

Diabetes
 Hypertension
 Pharmacogenetics
 Alcoholism
 Lupus

2. *Develop new and improved approaches for detecting or diagnosing the onset of progression of diseases and disabilities in minority populations.*

Prostate Cancer
 Mental Disorders
 Language Disorders

3. *Develop new and improved approaches for preventing or delaying the onset or progression of diseases and disabilities that contribute to health disparities in minority populations.*

Diabetes
 Obesity
 Project Northland
 Dental Caries
 Asthma
 HIV Vaccine Development

4. *Develop new and improved approaches for treating diseases and disabilities that contribute to health disparities in minority populations.*

Mental Illness
 Cancer Survivorship
 End of Life/Palliative Care Research
 Tuberculosis
 Diet and Hypertension
 Alternative Medicine
 HIV Infection and Metabolic Change
 Treatment of Diabetes and its Complications

Epidemiology and Risk Factors. Population studies are essential to tease out the underlying causes of disparities in health. Such studies inquire into biological differences in disease and risk; differences in morbidity and mortality according to race, sex, and ethnicity; and environmental and socio-economic differences and their relation to health and disease. These studies also provide essential information to help frame the questions for additional basic and applied research.

Stroke. Several new trans-Institute initiatives will encourage researchers to explore the causes of stroke disparities in racial and ethnic minorities by analyzing the effects of genetics, environment, and their interactions in health outcomes. One study will focus on the role of migration and acculturation of minority populations in the United States, as risk factors for stroke. Also, to better understand the risk factors for stroke in minority populations, NIH will support the first phase of a pilot program at the Morehouse School of Medicine. This 6-year multidisciplinary research program will assess established and potential new risk factors for stroke in minority populations while helping to develop expertise on population research methodology at a minority medical school. Also, in partnership with the Alaskan Indian Health Service, NIH will support a *Stroke Registry for Alaska Natives* living in Alaska. The registry will allow the determination of incidence, prevalence, distribution, and risk factors pertinent to Alaska Natives. Given the unique characteristics of this population, including their traditional diet rich in fish and marine mammals and relatively recent exposure to Western habits, it is possible that the registry may help identify new risk and protective factors for stroke.

Cardiovascular Disease. The NIH will continue its support of the Jackson Heart Study, a prospective review of the environmental and genetic factors affecting the disproportionate incidence of cardiovascular diseases in African

American men and women. In addition, research will be supported to characterize traits (intrinsic aging changes versus cardiovascular disease risk factor burden) in a biracial (African American-Caucasian) population that may influence progression of sub-clinical cardiovascular disease in an aging population. NIH will expand support of a well-characterized biracial (African American-Caucasian) population that has been followed for cardiovascular disease risk factors and lifestyles, through the Bogalusa Heart Study, over the past 25 years into middle age and beyond. New research will provide insight into the interaction between normal aging, including the growth and maturation process in childhood, and predisposing risk factors that may influence development of sub-clinical cardiovascular disease in an African American-Caucasian population reaching middle age. This initiative will provide a greater understanding of the evolution of cardiovascular disease risk in normal aging and may also lead to improved lifestyle programs for successful aging and longevity, including cardiovascular disease prevention.

Hepatitis C. Various population-based surveys indicate that the Hepatitis C virus has a greater impact on minority populations in the United States. African Americans are infected with the hepatitis C virus at twice the rate of non-minority populations, and they are less responsive to therapy. This differential response to treatment remains unexplained and requires further investigation as part of our health disparities research plan. The NIH is supporting four Hepatitis C Cooperative Research Centers, two of which have minority populations as a focus. The first Center is following a large, urban, predominantly African American group that injects drugs; the second is following an Alaska Native cohort. The Centers are examining the natural history of the infection and the persistence and pathogenesis of both the virus and the host. The NIH will also start a Hepatitis C Virus Recovery and Research Network to acquire new information about population factors contributing

to different infection and recovery rates among minorities.

Cancer Surveillance. The NIH and the National Center for Health Statistics (NCHS) of the CDC will collaborate to improve coordination of national cancer surveillance research and control programs, with the primary objective of describing and monitoring cancer-related disparities among individuals and populations. NIH, CDC, and NCHS will produce a multi-year plan for collaborative activities in the analysis and dissemination of cancer-related health survey, health survey methodology, and techniques for improving the quality and availability of data pertinent to measuring population-based health disparities. In addition, NIH will expand the Surveillance, Epidemiology, and End Results (SEER) Program to include populations with differential cancer rates that are currently underrepresented (e.g., Hispanics, rural African Americans, American Indians, high poverty, and high cancer death rates). Expansion of the SEER Program will strengthen the existing national infrastructure for surveillance research, which in turn will lead to improved understanding of health disparities in cancer outcomes among major ethnic populations.

Prostate Cancer. Prostate cancer is the most commonly diagnosed form of cancer in men in the United States and, following lung cancer, is the second most common cause of cancer-related death. African American men suffer disproportionately from this disease, with some of the highest incidence and mortality rates reported in the world. Among African Americans, the highest death rates tend to cluster in the southeastern United States, with mortality in parts of this region approaching three times the national death rate for Caucasians. The reasons for the differential geographic and ethnic risks are unknown, although variation in dietary fat and cooking practices, selenium intake, agricultural exposures, sexually transmitted factors, endogenous hormones and growth factors,

physical activity, and body size may be involved, as well as inter-relationships with genetic susceptibility factors. Previous large-scale studies of prostate cancer in African Americans and Caucasians have been limited to questionnaire-based studies. To better understand the factors contributing to these differing risks for and rates of prostate cancer, NIH will support a comprehensive, biologically-based epidemiologic investigation in African Americans and Caucasians in the southeastern, northwestern, and other parts of the United States to identify determinants of prostate cancer in high-risk and low-risk populations.

Drug Abuse and Addiction. NIH will support research to identify the short- and long-term effects of drug use, abuse, addiction, and violence and their interrelationships on the overall health (including physical, mental and emotional health) of men, women, and children in racial/ethnic populations. Specifically, research will be expanded to: investigate health and developmental disparities across racial/ethnic groups for children and adolescents who have experienced prenatal drug exposure and/or early use of illicit drugs by gender within these groups; identify and review the state of knowledge and availability of data on the coexistence of substance abuse and mental/emotional disorders and the presence of health disparities across and within racial/ethnic groups including analyses by gender; and identify the impact of the drug using environment on racial/ethnic women and men living under those conditions.

Sexually Transmitted Diseases. The NIH will conduct a study to expand the understanding of factors that contribute to high-risk sexual behavior. Part of this study will measure the magnitude of risk reduction in the context of monthly support groups. Six hundred African-American and Mexican-American women with a current STD will be enrolled from health clinics in San Antonio, Texas

Oral Health. The NIH is establishing Centers for Research to Reduce Oral Health Disparities. The objectives of these Centers are: 1) to support research to understand the factors involved in craniofacial, oral and dental health disparities, and to design interventions to reduce such disparities; and 2) to develop and strengthen the national research capacity by expanding opportunities for scientists in underrepresented groups within the scientific workforce. This initiative will encourage inter-disciplinary research across components of academic health centers and will involve community-based research with State and local health departments, including health financing agencies. It will also provide opportunities for collaboration among NIH Institutes and Centers and other Federal agencies.

Osteoarthritis. The NIH is encouraging research studies to evaluate risk factors for the development and progression of osteoarthritis in vulnerable populations. Studies have shown that African Americans have much lower rates of total knee replacement than Caucasians, even when adjusted for age, sex, and insurance coverage. Total joint replacement (TJR) is a successful procedure for end-stage arthritis of the major weight-bearing joints. More than 500,000 hip and knee replacements are done annually in the United States. For reasons that are not fully understood, most of these procedures are performed in Caucasians. Serious questions have been raised concerning the disparate rates for TJR between racial groups and geographic locations that seem to have no direct relationship to incidence of disease. Therefore, the NIH will fund research to develop a method for conducting an in-depth analysis of the rate differential that could lead to an identification of the underlying reasons for this disparity. The results of this research could be used to help ensure that the benefits of TJR can be extended to the segment of the population that appears to have limited access to this procedure.

Glaucoma. The Baltimore, Beaver Dam, and Barbados Eye Studies have established race as a significant risk factor for primary open-angle glaucoma, with all three studies confirming substantially higher rates of the disease among African Americans. There is a dearth of information about the prevalence and incidence of glaucoma in Hispanic and Native American populations; therefore, studies will be initiated in these populations to obtain this critical information. Large-scale initiatives proposed by NIH will improve understanding of the nature and course of glaucoma, incorporating studies of comorbidity, natural history, and genetics, with special emphasis on Hispanic, Native American, and African American populations.

Youth Violence. The NIH Youth Violence Consortium will develop a collaborative effort to understand the antecedents, social and neurobiological causes, and outcomes of violent youth behavior. The NIH will also support another collaborative effort across racial and ethnic lines to study the short- and long-term effects of domestic violence during pregnancy and the effects of domestic and community violence on children.

Alternative Medicine. The NIH will support epidemiological studies of complementary and alternative medicine (CAM) in underserved populations. Specifically, investigators will be encouraged to collect and analyze data on demographics, health and social characteristics, race/ethnicity, pre-existing illness, and CAM utilization among the underserved. A national survey of CAM utilization is planned. In addition, comparative studies of immigrant populations in their country of origin and in their countries of relocation will assist in clarifying the roles of environmental, psychosocial, and genetic factors in the effectiveness of CAM.

Environment and Socioeconomic Status. The poor often have worse health than other population groups, resulting in shorter life

expectancy, higher cancer rates, more birth defects, greater infant mortality, and higher incidence of asthma, diabetes, and cardiovascular disease. The ways in which poverty contributes to these health disparities are still poorly understood. Research that seeks to better understand the effects of social and physical environments on human health and disease is an important avenue of pursuit toward ameliorating the health disparities suffered by the economically disadvantaged of this nation.

Biomarkers for Diseases. The NIH will support research into the fetal antecedents of, and biomarkers for, differences in hypertension, stroke, diabetes, and coronary heart disease. Studies will be supported to identify how deficiencies in the uterus influence the developing fetus and contribute to future chronic disease, define normal fetal growth, and identify other biomarkers in minority and non-minority groups. Another initiative will determine if maternal-fetal response to external stimuli vary among racial and ethnic groups. An additional effort will extend the Science and Ecology of Early Development project, which examines the relationship of poverty to other factors that affect the development of children.

Centers for Health Disparity Research. The NIH will create Centers for Health Disparity Research and Intervention to foster an interdisciplinary approach to the study of health disparities. These Centers will bring researchers together to determine the mechanisms by which the interaction of socioeconomic status (SES), social, and physical environments lead to health disparities. The social environment includes individual and community-level characteristics, e.g., SES, education, coping resources and support systems, residential factors, cultural variables, institutional and political forces such as racism, familial factors, and media influences. The physical environment includes physical agents (e.g., radiation), chemical agents (e.g., pesticides) and biological agents (e.g., pathogens)

to which individuals are exposed in a multitude of settings, including home, school, and workplace. Such research will clarify biological and behavioral processes that lead to health disparities, and this information can be used as a basis for developing intervention strategies. The centers will then conduct and evaluate community-based intervention research projects intended to reduce the unequal burden of morbidity and mortality borne by low SES and minority populations.

Cognition. The NIH will coordinate demographic and epidemiological studies on the racial, ethnic, geographic, socioeconomic, educational, and health factors affecting cognitive, sensory, and motor health and the development of mild cognitive impairment, Alzheimer's disease, and other neurodegenerative diseases of aging. A common goal will be to understand cognition in the contexts of culture and environment in order to understand how individuals adapt in various ways to maintain cognitive functioning as they age.

Mechanisms of Disease. Identifying differences in how disease and disability begins, manifests, and progresses in different populations, and understanding the reasons for such differences, are important steps toward reducing health disparities.

Perinatal Research. To better understand the pathophysiological, social, and behavioral factors that lead to preterm births and low birthweight, the NIH will significantly expand the scope of current efforts in perinatal research. Specifically, the agency will: 1) clarify the causes of health disparities in preterm births and in adverse neonatal outcomes arising from infectious/inflammatory disease processes, through multidisciplinary, collaborative research, and by augmenting current Neonatal and Maternal Fetal Medicine Network protocols; 2) develop and implement clinical trials to prevent preterm births and adverse neonatal outcomes

arising from infectious/inflammatory disease processes, focusing on minority women, and testing different treatment regimens, and preventive and counseling strategies; 3) identify genetic factors that predispose women and their infants to preterm births and low birth weight, focusing on racial and ethnic populations; and 4) expand the *D.C. Initiative* with new interventions, focusing on African American and Hispanic teens, that simultaneously address psychosocial and behavioral risk factors to prevent preterm births and low birthweight.

Injury. Injury-related death rates are greater for underrepresented minorities (African Americans, Hispanics, and Native Americans, and Alaska Natives than for Caucasians. While access to appropriate medical care is likely to be an important factor in these differences, the question of whether underlying differences exist between racial and ethnic groups in the physiological response to injury remains to be adequately addressed. Preliminary clinical studies on humans have suggested that there are several potential mechanisms that could explain gender or racial differences to injury. Beyond the immediate post-injury period, gender, racial, or ethnic characteristics may influence the restoration and repair of tissue as well. NIH will support research to: 1) determine the genetic basis for the host response to injury, with particular reference to genetic variations known to be prevalent in underrepresented minority populations; 2) assess whether the perception and management of pain following burn injury differs based on gender, race, or ethnicity, or is entirely individualized; and 3) investigate the molecular and cellular basis of keloid formation, mechanisms of severe wound contraction, and the means to allow skin grafts to regain pre-burn appearance, emphasizing the need to expand into considerations of unique properties and characteristics of the skin of subpopulations.

Stress. Racial and ethnic minorities tend to experience more stressful situations compared to

the majority population. Basic behavioral science research has documented certain cultural and ethnic variations in processes involved in coping with stress, e.g., cognitive, emotional, and social processes, perception of self, and motivation. Constant effort to avoid or cope with stress can cause and exacerbate psychological consequences. NIH plans to increase understanding of the mechanisms by which culturally-related stressful situations affect health by: 1) studying the basic psychological processes described above, with a focus on clarifying the complex processes that contribute to disparities in mental health; 2) developing diagnostic measures of mental disorders that are valid within racial and ethnic groups so that disparities can be more precisely documented and assessed; and 3) examining factors that foster adaptive coping, with the aim of developing new prevention and treatment strategies.

Scleroderma. Social, racial, cultural, immunogenetic, and clinical variables may affect presentation and progression of scleroderma. The NIH plans to increase support for research to identify biological factors in predisposition for, as well as the onset and progression of, scleroderma, thus allowing the design of appropriate interventions.

Genetic Variation. The Human Genome Project and other initiatives are locating, identifying, and describing the functions of the estimated 50,000 to 100,000 human genes. This knowledge is leading to new insights into how variations in genes may contribute to significant differences in how individuals and populations experience disease and disability, are affected by environmental factors, and respond to therapies and preventive measures. Understanding variations in gene expression in diverse populations is thus an important step towards reducing health disparities.

There is little population-based data on genetic and epidemiological factors that play a role in

disproportionate rates and burdens of diseases like cancer and diabetes among minorities. In response, the NIH has launched initiatives to collect population-based data while maximizing the participation of minority researchers, physicians, and patients. The identification of genes underlying susceptibility to common diseases in minority populations and an understanding of the function of these genes and their interaction with environmental factors will lead to improved management and treatment of disease.

Diabetes. The NIH will promote and further expand research on the causes of diabetes in minority populations and its program on type 2 diabetes in children. These studies will help in determining the underlying physiologic, metabolic, genetic, psychosocial, and behavioral factors that cause the racial and ethnic differences in the incidence of type 2 diabetes.

Hypertension. Two programs supported by NIH will continue to examine the genetic basis of hypertension. The Molecular Genetics of Hypertension initiative will study causes and development of the disease to improve diagnosis and treatment, with one subproject focusing only on African Americans. The Family Blood Pressure Program, in which 61 percent of the participants are African American, is a collaborative network to identify genes associated with high blood pressure.

Pharmacogenetics. Pharmacogenetics is the study of the effects of inheritance on drug action. Individual variability occurs in both the desired therapeutic effects of drugs, as well as in their toxicity (or side effects). Genetic polymorphisms significantly affect the elimination of several major classes of important drugs in clinical use today, including antidepressants, antipsychotics, several cardiovascular drugs, antiepileptics, and anti-ulcer drugs. These genetic differences can have serious clinical consequences, particularly in chronic dosing situations. The NIH will support

pharmacogenetics initiatives that are designed to discover what role genetic variation plays in drug responses. For example, NIH will expand the scope of the Pharmacogenetics Research Network and Knowledge Base that collects, interprets, and stores information about inherited variations that determine therapeutic and adverse responses to drugs. Candidate genes and gene products will be evaluated that might be responsible for the therapeutic mechanism of action of drugs used to treat mental disorders in diverse subpopulations.

Alcoholism. Recent data suggest that there are genetic differences between ethnic groups in their sensitivity to alcohol. These potential ethnic differences in alcohol sensitivity may result, in part, from genetic differences in metabolic factors and from differences in the central nervous system's reactivity to alcohol. Measurements of the physiological and behavioral outcome of gene activity will yield more refined markers that indicate genetic ethnic differences in susceptibility to alcoholism, potentially leading to means of prevention and treatment modalities. NIH will support studies to determine the specific genetic factors that contribute to the high risk for alcoholism in certain minority/ethnic groups. Other efforts will assess gender differences in response to alcohol in diverse racial populations, and establish how sociocultural factors interact with genetic variations in alcohol-metabolizing enzymes to produce differences in drinking.

Lupus. Like scleroderma, another autoimmune disorder, many variables may affect presentation and progress of lupus, but genetic factors seem to be more important than other determinants especially at the onset. Identification of the biological factors for predisposition and onset will make possible the design of interventions. The NIH will continue supporting the Lupus Registry and Repository, a national resource of blood from lupus patients and their families, about half of whom are African American; a new objective is

to increase the number of Mexican American and Puerto Rican families.

2. *Develop new and improved approaches for detecting or diagnosing the onset or progression of diseases and disabilities that contribute to health disparities in minority populations.*

Research to create new diagnostic tools is closely intertwined with basic disease research; diagnostic tools are most commonly developed after the mechanisms of the specific disease process are understood. Numerous efforts are planned to focus on developing a broad array of approaches to more effectively detect, diagnose, and assess diseases that disproportionately affect racial and ethnic subpopulations. This is important because early and accurate diagnosis and detection are often key requirements for effective treatment, delay, and control of disease and disability. Some of the most life-threatening and disabling illnesses affecting racial and ethnic minorities can only be controlled or cured if they are diagnosed and treated in the earliest stages.

Prostate Cancer. The Baltimore Longitudinal Study of Aging has produced findings about prostate specific antigen (PSA) that have improved the ability to screen Caucasian men for prostate cancer and hyperplasia and assess risks. We still do not know how to apply longitudinal measures of PSA and prostate volume in assessing risks for African American men, who have the highest rate of prostate cancer in the world and a higher PSA baseline, yet longitudinal collection of data can equip physicians to identify the best modes of screening and diagnosis. In order to help determine if certain screening techniques can reduce the number of deaths from prostate cancer, the Prostate, Colorectal, and Ovarian Screening Trial will enroll 75,000 men who will be screened for prostate cancer. The NIH has initiated minority recruitment efforts for this trial specifically to determine the mortality

effects of screening among African American men.

Mental Disorders. The burden of mental disorders falls disproportionately on minorities, yet there are significant discrepancies between rates of mental disorders and utilization of mental health services. African American men show a consistent underutilization and, while data on Asians and Hispanics are inadequate, it appears that Asians have the lowest utilization rates of all. The NIH plans to obtain baseline assessments of the prevalence of mental disorders among minorities and of disabilities associated with mental disorders, including substance abuse and substance abuse disorders, among minorities. Representative epidemiological studies of mental disorders, substance abuse, disability, and service utilization will provide data to assess the disparities of mental disorders, insights into the causes of the disparities, and baselines against which remedies for the disparities can be measured.

Language Disorders. As the U.S. becomes more culturally, racially, and linguistically diverse, it is becoming increasingly difficult to discriminate between language disorders and language differences in children. Problems in language assessment arise because the majority of currently available measures are designed for identifying speech and language problems in standard English speakers. The NIH is supporting projects to develop language tests for non-standard English. Investigators are collecting cross-sectional data on language abilities in normally developing four- to six-year-old speakers whose primary language is not English or is a non-standard form of English. The data are aimed at developing items for a language assessment instrument or procedure that could be used to differentiate between language impairment and normal language development. Cognitive and developmental research is just starting to identify the best instructional

approaches to ensure the school readiness of Hispanic children.

3. *Develop new and improved approaches for preventing or delaying the onset or progression of diseases and disabilities that contribute to health disparities in minority populations.*

To develop ways of preventing, delaying, and halting disease requires the contributions of many disciplines. Epidemiology can identify the magnitude, and possibly the variability, of a disease in different populations and may identify those at greatest risk. An understanding of disease mechanisms may produce means of preventing or delaying the onset of disease by determining the cause of a disease, how it affects cells or organs, or whether there is a genetic predisposition for the disease. Behavioral studies are important since intervention may require new medication or change in behavior. Clinical research and trials are the only means of evaluating new therapies or behavioral approaches.

Diabetes. The NIH supports an extensive portfolio on diabetes research. Greater understanding of the causes of diabetes are critical in accounting for the higher rates of the disease among minorities. The Diabetes Prevention Program, a clinical trial, is a large, multi-center study of diabetes prevention at 27 sites in the United States, with 45 percent of the participants drawn from minority populations. The Diabetes Research and Training Centers are conducting behavioral research to advance knowledge of the behavioral and psychosocial factors that may contribute to onset and aid in control of diabetes among minorities.

Obesity. The NIH supports a range of research studies that focus on the prevention of obesity among minority populations. For example, the Growth and Health Study seeks to determine if racial disparity in obesity among pubescent girls

results from differences in diet and physical activity or from socioeconomic or other environmental factors and if these distinctions, in turn, lead to racial differences in stroke and other cardiovascular risks, like high blood pressure and blood lipid levels. The study has been extended to track the participants into early adulthood when changes, related to obesity, in stroke and cardiovascular risk factors seem to occur.

Another effort among African American girls at high risk for obesity is testing the effectiveness of various weight-control interventions during the critical transition from prepuberty to puberty. The Obesity Prevention in Young American Indians program is assessing the effectiveness of intervention in schools as a primary preventive measure against obesity in elementary school children. For years, the NIH has conducted clinical and epidemiological research on obesity and diabetes among the Pima Indians of Arizona because type 2 diabetes is extremely prevalent among them. The NIH has added genetic studies and is planning to increase emphasis on intervention trials and studies of prevention and treatment with the aim of determining the biological and behavioral causes of the disproportionately high incidence of diabetes among the Pima.

Project Northland. Project Northland combined an alcohol prevention curriculum in schools with parental and community involvement, and school policy change and was found to be effective in small, predominantly Caucasian communities in Minnesota. The NIH is, therefore, planning to test prevention and intervention programs among minority youth. With some adjustments, this approach to delaying initiation to alcohol among adolescents will be tested in urban neighborhoods and school districts with substantial numbers of minorities.

Dental Caries. NIH will support research to address the treatment and prevention of dental caries as a way of directly reducing the incidence and prevalence of the disease within SES and

ethnically/racially distinct groups and as a means of stopping or preventing its sequelae. In this regard, the research will, among other things, focus on access to care and prevention issues (e.g., increasing access to dental care; information dissemination to dental clinicians), the development and testing of interventions aimed at modifying risk-taking behaviors both among children and their caretakers that lead to increased incidences of dental caries and the development and testing of interventions directly relevant to the treatment and prevention of the disease itself. In addition, NIH is supporting research to develop safe, low cost, stable caries vaccines for high-risk individuals.

Asthma. Asthma morbidity and mortality are particularly high among poor, urban African Americans. To address this disparity, the NIH established the National Cooperative Inner-City Asthma Study, which identified many factors associated with the severity of asthma among African American and Hispanic children, including the combination of cockroach allergy and high levels of cockroach allergen. The study also implemented educational, behavioral, and environmental interventions to alter the factors identified as major contributors to severe asthma and demonstrated that an asthma counselor, in addition to environmental controls, substantially helped to reduce asthma morbidity. The Asthma Clinical Research Network will be continued. This involves establishing an interactive network of asthma clinical research groups, including one at Harlem Hospital, which serves a predominantly minority population, to conduct studies of novel therapies for asthma and disseminate findings to the practicing community. In addition, the Childhood Asthma Management Program which seeks to determine if regular use of either of two types of anti-inflammatory medications results in greater lung function, less bronchial hyperresponsiveness, and improved quality of life for asthmatic children; 33 percent of the participants are minorities.

HIV Vaccine Development. NIH will initiate an HIV vaccine efficacy trial through the HIV Vaccine Trials Network. With other scientists, the NIH will also study the scope and relationship of viral and human genetic variation in relation to vaccine development, an important research effort given the higher burden of HIV among minorities in the United States.

4. *Develop new and improved approaches for treating diseases and disabilities that contribute to health disparities in minority populations.*

The aim of much of NIH research is the development of new and improved therapeutics. The objective of reducing health disparities affecting racial and ethnic minorities through improved treatments requires advances in many areas, from chemistry to structural biology to bioengineering and pharmacology. The successful development of new therapies will also depend on a strong foundation of understanding disease mechanisms and how normal and abnormal biological functions may vary in different populations. Clinical research is the final common pathway for assessing the efficacy of new treatment approaches. New approaches—whether drugs, devices, or changes in behavior—must ultimately be evaluated in a variety of subpopulations. In addition, health services research is needed to study the ultimate effect of any new approach on the burden of a disease, both to the individual and to society.

Mental Illness. Clinical research supported by NIH and others has demonstrated the efficacy of various interventions for mental illnesses. However, few mental health treatment studies have enrolled enough minorities to determine how well various treatments work in these populations, in part because minorities are less likely to enroll in clinical trials. Of particular interest is whether different groups have less response to commonly used interventions such as pharmacological medications and psychotherapeutic approaches.

Moreover, research has shown that providers do not always deliver what is considered to be the best interventions for a particular illness. This gap in quality of care has been shown to be particularly problematic in relation to services provided to minority groups. NIH research will determine why recruitment and retention of minority group members into randomized clinical trials of mental health treatments is so difficult; determine the most culturally relevant, appropriate, and acceptable outcomes regarding symptoms and functioning; see if there are different outcomes for minority groups when treatment interventions are provided in the community and, if so, why; determine whether providers use different interventions for various minority groups and if so, why; and determine the impact of cultural competence training on the quality of care and treatment outcome for minority patients.

Cancer Survivorship. Research is needed to explain how ethnic and cultural factors affect cancer survivorship. NIH will support studies on the impact of cultural, socioeconomic, and institutional factors on the quality and length of cancer survivorship in underserved communities. In addition, support will be provided to develop strategies to help cancer patients and their families make the transition to extended and long-term survivorship. Developmental research will elucidate the ethnic and cultural context of survivorship, and the similarities and differences in the survivorship experience across ethnic minority and medically underserved groups. A future effort will expand psychosocial and behavioral intervention research in minority and underserved cancer survivors and their families, which has the potential to improve quality and length of survival.

End of Life/Palliative Care Research. The NIH is focusing on cultural/ethnic differences in understanding and managing end of life issues, including clinical management of physical and psychological symptoms, communication, ethics and clinical decision-making, caregiver support, and care delivery issues.

Tuberculosis. The Tuberculosis Research Unit, an international, multi-disciplinary team, is developing or evaluating new assays, markers, preventions, and therapies, including a new drug that is taken less often, which may address a major compliance problem among minorities. The NIH is also supporting epidemiological studies on genetic and environmental factors that contribute to tuberculosis.

Diet and Hypertension. Two initiatives will continue to assess diet in controlling hypertension among minorities. One, in which 50 percent of the participants are African American, compares the effects of three levels of sodium intake and two diets, a reference diet and the DASH diet, which is low in fat and high in fruits and vegetables. The second, Premier: Lifestyle Interventions for Blood Pressure Control, compares the effectiveness of two lifestyle interventions (reduced salt, increased exercise, moderate alcohol, weight loss) on blood pressure control when one intervention also includes the DASH diet; 41 percent of participants are African American.

Alternative Medicine. NIH will support studies of alternative and complementary medicine in which minority groups will be oversampled to allow statistical evaluation of different patient populations. For example, evidence suggests that nebulized magnesium has a significant bronchodilatory effect in acute asthma. However, this effect has not been tested in a well-designed clinical trial. This initiative would investigate magnesium's efficacy for treating asthma in a large, randomized, clinical trial in children. African American children would be oversampled in this trial.

HIV Infection and Metabolic Change. Some therapies for HIV have produced metabolic complications, including peripheral weight loss, possible bone loss, atherogenic lipid profiles, and diabetes. Since Hispanic and African Americans are disproportionately affected by AIDS and at greater risk of diabetes and cardiovascular disease, these metabolic complications are

particularly serious for them. The NIH has funded a nationwide, multi-center study, Fat Redistribution and Metabolic Change in HIV Infection (FRAM), to investigate the problem. The FRAM study should provide insights into the cause and potential disparity in metabolic abnormalities associated with HIV and provide the foundation for targeted studies on etiology and treatment in minority groups. Improved recruitment strategies and more qualified investigators working with minorities will raise the likelihood of effective treatment for metabolic abnormalities in minorities with HIV.

Treatment of Diabetes and its

Complications. Understanding the etiology of complications of type 2 diabetes is a critical step in determining why minority populations are at higher risk for such complications. It is also the first step in developing tailored interventions for these specific populations. The NIH has initiatives to encourage research on the factors leading to higher rates of diabetic complications in minority populations, the pathogenesis and treatment of complications of type 2 diabetes in children, the prevention and treatment of amputations in diabetic individuals with foot ulcers, the role of endothelial cell dysfunction in diabetic complications, and the role of growth factors in the development of diabetes complications.

End Stage Renal Disease. The NIH has a major intervention trial, the African American Study of Kidney Disease and Hypertension, which is investigating what class of antihypertensive agents, and which level of blood pressure treatment will reduce or prevent the development of hypertensive End Stage Renal Disease. Future efforts will include determination of genetic and other factors that will help prevent the development and progression of the disease.

Research Infrastructure

Just as a building is only as solid as its foundation, the success of the biomedical research enterprise depends on a solid infrastructure. Broadly defined, research infrastructure includes biomedical researchers and personnel and the means and resources for supporting and training them, as well as research facilities, equipment, and supportive services. NIH recognizes that our ability to reduce health disparities through the research proposed in this plan requires a strong commitment to training and supporting investigators in these areas. Our ability to sustain and even increase the momentum of recent scientific progress and our international leadership in medical research depends upon recruitment, training, support, and retention of diverse biomedical investigators. To ensure this, the NIH has identified two objectives (see Table 1).

To ensure success in meeting these objectives, a broad range of infrastructure initiatives are being planned and implemented. Examples are provided below, and these are summarized in Table 3.

Selected Examples of Research Infrastructure Initiatives by Objective

1. *Support research training and career development.*

The aim of NIH's support of training and career development programs is twofold: to produce new, highly trained investigators who are likely to perform research that will lead to improvements in health and to maintain a highly trained population of scientists that can address the Nation's current and future health-related research needs. Central to this is the NIH's commitment to training and supporting a research community that reflects the Nation's social diversity.

Accordingly, NIH supports a number of training programs specifically designed to provide support to minority graduate and postdoctoral students and to recruit them into research at earlier career levels. NIH also supports programs designed to enhance the retention of women in biomedical research careers.

Support for Doctoral Dissertation Research and Travel Awards. Existing programs at NIH to support minority investigators will be expanded, including doctoral dissertation support and travel awards for students and faculty to conferences and training sessions in health disparities.

Minority Access to Research Careers (MARC). The NIH will continue and extend its efforts to strengthen the competitiveness of researchers from minority institutions by expanding its innovative workshops on grant writing and evaluation. A new post-baccalaureate program is planned as part of the MARC Program. Support for the Bridges Program will be doubled in response to increases in the number of high quality applications.

Minority Supplements Program. NIH will also be expanding the *Minority Supplement Program*, which supports undergraduate and predoctoral students and faculty for summer research experiences.

Clinical Research Training. The NIH Clinical Center will serve as a core facility for a number of new clinical investigator training programs for minority scientists. This includes expanding the visiting investigator program, which aims to add to the corps of scientists involved in the Division of Intramural Research. Through this program, a greater emphasis will be placed on attracting investigators as visitors who have an interest in health disparities research. In addition, the NIH will provide support for the Transitional Career Development Award in Women's Health Research for which minorities and women are encouraged to apply. This career development program gives investigators the opportunity to develop solid clinical

Table 3
Selected Examples of NIH Research Infrastructure Initiatives to
Reduce and Ultimately Eliminate Health Disparities

1. *Support research training and career development.*

Support for Doctoral Dissertation Research
 and Travel Awards
 Minority Access to Research Careers
 (MARC)
 Minority Supplements Program
 Clinical Research Training
 Infectious and Sexually Transmitted Diseases
 Mental Health
 Neuroscience
 International Research
 Clinical Research
 Aging Research
 Genomic and Genetic Research
 Introduction to Biomedical Research
 Short-term Training for Minority Students
 Minority Undergraduate Biomedical
 Education Program
 Minority Medical School Research Program
 Diabetes and Minority Investigators
 Native American Researchers
 Environmental Health
 Meyerhoff Scholars Program
 Environmental Health Sciences
 Genetic Factors: Diabetes Mellitus and
 Prostate Cancer
 Prevention of Violence and Unintentional
 Injury
 Rehabilitation Research
 Information Resources for Minority Students
 Rehabilitation Research
 Information Resources for Minority Students

2. *Provide support for institutional resources (extramural and intramural).*

Neuroscience
 Stroke
 Alcohol
 Diet and Stroke
 Strengthen Science Curricula
 HIV and AIDS Research
 Enhance Capacity of Minority and
 Underserved Institutions to Participate in
 Communications and Networking
 Technologies
 Training Minority Clinical Trial Investigators
 Recruitment of Minorities into Clinical Trials
 Community-based Research Infrastructure
 Building
 Institutional Development Awards
 Minority Representation in Peer Review

research skills during two years of study and research within the environment of the NIH. Intramural Research Programs (IRP). The award will also include a follow-on two-year period of salary and research support at an academic institution of the candidate's choice.

Infectious and Sexually Transmitted Diseases. Following the NIH-supported model partnership between the Howard University School of Medicine and the Sexually Transmitted Disease Comprehensive Research Centers, the NIH will expand research training programs in infectious diseases such as HIV and tuberculosis as well as sexually transmitted diseases.

Mental Health. Training programs for health disparities in mental health will be initiated. An alliance will be established between two currently existing training programs: the Career Opportunities in Research (COR) undergraduate programs and the Training and Educational Alliances for Mental Health Research predoctoral graduate programs. The goal is to facilitate the transition of students into mental health research laboratories where they can receive graduate and postdoctoral research mentoring. The Mental Health Education Award mechanism will be used to support innovative strategies for COR students and enable the faculty to gain access to graduate level mental health research expertise and instructional networks. Predoctoral fellowship training programs will be implemented to combine medical school and predoctoral support for students in areas that contribute to understanding health disparities in mental health.

Neuroscience. The NIH will continue training programs for minority investigators in neuroscience research in areas such as stroke, neurological manifestations of AIDS, drug abuse and addiction, biomedical and behavioral sciences, and alcohol research. There will also be traineeships in biotechnology programs to support faculty and students from minority schools.

International Research. Efforts are underway to expand international global health research initiatives (e.g., minority international research and training programs) in countries whose populations share similar ethnic backgrounds as U.S. minority populations with health disparities.

Clinical Research. The Mentored Medical Student and Clinical Research Scholars Programs will provide increased exposure to clinical research for minority medical students and junior faculty conducting clinical research.

Ageing Research. The NIH will continue to offer opportunities in ageing research to minority candidates through the Claude Pepper Older American Independence Centers Program, which provides first-rate opportunities in a variety of research methods and analytic approaches useful in understanding aging.

Genomic and Genetic Research. A series of research training programs will help expand efforts to understand the biological origins of health disparities, e.g., a career award in genomic research or in research on the ethical, legal, and social issues (ELSI) raised by genetic and genomic research. The program will recruit minority postdoctoral scientists to work with a mentor in a specialized field of genetic or ELSI research. In addition, the Genomics Short Course for Faculty at Minority Institutions will offer courses in the latest genomic developments, genetic technology, medical genetics, and gene therapy and in ethics and grant writing.

Introduction to Biomedical Research. NIH will continue to support the long-standing and highly successful Introduction to Biomedical Research Program. This program, in existence for 21 years, brings outstanding minority undergraduate students to the NIH campus for a week long program of mentoring, advice, and cutting-edge scientific talks.

Short-term Training for Minority Students. Support will be provided for the Short-term Training for Minority Students Program, which

provides short-term research support to underrepresented minority undergraduate and graduate students and students in health professional schools to expose them to career opportunities in cardiovascular, pulmonary, hematologic, and sleep disorders research.

Minority Undergraduate Biomedical Education Program. The Minority Undergraduate Biomedical Education Program will develop a pilot program that encourages minority institutions to recruit and retain talented undergraduate students into the biomedical and behavioral sciences.

Minority Medical School Research Program. This program will augment and strengthen the research capabilities of faculty, students, and fellows at minority medical institutions that offer the M.D. or equivalent medical degree by supporting the enhancement of ongoing, and/or development of new basic, clinical, and population-based research programs in heart, lung, blood, and sleep disorders.

Diabetes and Minority Investigators. Because of the extremely high incidence and prevalence of type 2 diabetes mellitus and obesity in the Pima Indians of Arizona, the NIH has conducted for many years an intramural program of research on diabetes and obesity in this American Indian population. In recent years, these clinical and epidemiological studies have been extended to include genetic studies. Also, there are current plans for increased emphasis on intervention trials, and studies of prevention and treatment of diabetes and its complications in this population. This Pima Indian population is currently participating in the Diabetes Prevention Program (DPP) clinical trial. A major new initiative is to use the DPP as a vehicle to training minority (American Indian and Native Hawaiian) investigators to continue relevant investigations in their respective communities.

Native American Researchers. The Indian Health Service and the NIH are collaborating to increase the research capacities and skills of

tribal organizations and Native American researchers in order to enable them to conduct first-rate research.

Environmental Health. The Advanced Research Cooperation in Environmental Health (ARCH) Program will expand to include more minority institutions. The program links research and minority institutions to support faculty development and to develop core facilities, e.g., tissue culture and molecular biology. Some of the existing collaborations are Xavier University and Tulane University, and Southern University at Baton Rouge and the University of Texas Medical Branch in Galveston.

Meyerhoff Scholars Program. The University of Maryland/Baltimore County is working with the NIH and the National Science Foundation to advance the Meyerhoff Scholars Program which encourages African American students to pursue education and careers in biomedical science.

Environmental Health Sciences. The NIH is expanding its collaboration with Morehouse School of Medicine to provide three-month internships for research and training in the quantitative and biomedical aspects of the environmental health sciences.

Genetic Factors: Diabetes Mellitus and Prostate Cancer. NIH will continue to work with Howard University to strengthen and expand two ongoing collaborative studies looking at the genetic factors associated with Diabetes Mellitus and Prostate Cancer in African Americans. These studies form the nucleus of an evolving National Human Genome Center at Howard University. This center will not only strengthen the research infrastructure of Howard University, but also provide cutting edge research and training opportunities for minority researchers.

Prevention of Violence and Unintentional Injury. Programs will be initiated at Historically Black Colleges and Universities, and at universities with an existing cadre of Hispanic or Native American Indian researchers to examine

ways to strengthen parenting within the community and to conduct research on effective ways to avoid violence and unintentional injury.

Rehabilitation Research. NIH will provide supplemental funding to newly established sites in the Regional Rehabilitation Network (which integrate basic science with clinical rehabilitation studies) to link with minority institutions to address targeted questions concerning minority populations.

Information Resources for Minority Students. The NIH is developing new ways to inform minority students and postdoctoral investigators about training opportunities in health disparities research, including web sites, informational documents, tracking systems for students to assess effects of programs, and conferences with African American students and faculty from Historically Black Colleges and Universities (HBCUs) and other academic centers, including participation in annual meetings of minority professional and medical associations.

2. Provide support for institutional resources (extramural and intramural).

In some cases, NIH supports research infrastructure needs of institutions by helping build new research programs, develop new laboratories, or create curricula to meet special needs. For specific programs, NIH Institutes and Centers place special emphasis on the consideration of applications received from institutions with substantial minority enrollment, including HBCUs, Hispanic Serving Institutions, and Tribal Colleges and Universities. Institutional support issues also include the scientific peer review process for health disparity grant applications. NIH is working to ensure appropriate levels of representation by minority scientists and experts in health disparities on scientific review groups (study sections).

Examples of the activities that NIH has developed to support research activities in health

disparities in the intramural and extramural programs include:

Neuroscience. The NIH will continue to establish Specialized Neuroscience Research Programs at minority institutions to augment existing programs and foster collaborative research, training, and research affiliations.

Alcohol. NIH will establish Collaborative Minority Institution Alcohol Research Development Programs, each consisting of an administrative core and several pilot studies developed collaboratively with established research scientists which will augment existing programs and strengthen the research and training capacities of minority institutions.

Strengthen Science Curricula. Through Support for Continuous Research Excellence (SCORE) Program and an information technology infrastructure program, the NIH will seek to enhance the science curricula and faculty research capacities at minority institutions.

HIV and AIDS Research. The NIH will increase support for HIV and AIDS research at minority institutions, with a special emphasis on clinical, molecular, vaccine development, drug development, opportunistic infection, and immunologic research. Another program will provide supplemental grants to applicants whose research is likely to yield immediate answers to critical biological and behavioral questions on infant and maternal mortality and major morbidities.

Capacity of Minority and Underserved Institutions to Participate in Advanced Computing Technologies. The rapid development of Internet and World Wide Web technologies make possible the quick, cost-effective distribution and exchange of biomedical information. Progress in telemedicine offers the promise of the cost-effective practice of medicine at a distance. New initiatives in this area include: expanding and enhancing efforts to improve

Internet connectivity and communications in sub-Saharan Africa, including at malaria research sites; developing and strengthening telecommunications linkages among the member institutions of the Minority Health Professions Foundation. This offers an excellent opportunity to bring information resources to underserved populations in the U.S. and will allow HBCUs to build telemedicine links to each other as well as to external resources; expanding efforts to improve Internet connectivity and access to health information services in Native American and Alaska Native communities; and funding outreach projects to form new institutional partnerships among medical libraries, public libraries, health professional associations, public health departments, churches, and community-based organizations, especially those located in inner cities.

Training Minority Clinical Trial

Investigators. The NIH has established a Clinical Trials Unit (CTU), a pilot program, at the Martin Luther King Hospital/Charles Drew University of the Medical Sciences. The CTU funded staff consist of Clinical Trialists, Clinicians, Epidemiologists, Biostatisticians, and support staff. In addition to collaborating with other clinical investigators, this is group is conducting pilot clinical trials and establishing a track record in order to independently compete for future funding of the CTU. A major function of the CTU is training of future minority clinical trial investigators.

Community-based Research Infrastructure

Building. NIH will create a research infrastructure, linked to community-based institutions, addressing the unique health needs of the African American, Hispanic, and Native American communities, that will: conduct basic research and design multi-disciplinary interventions addressing poor birth outcomes, provide opportunities for community-based research training, and provide research-based information to the community.

Institutional Development Awards. Although there are a number of medical schools within the 24 IdeA-eligible (Institutional Development Award) States, there is a limited number of NIH-supported research activities focused on diseases that disproportionately affect minorities. The Centers of Biomedical Research Excellence program will be used as a model to support investigators from the IdeA-eligible states to conduct health disparities research in academic medical centers and other comparable sites.

Minority Representation in Peer Review.

The NIH will emphasize having representative numbers of minority investigators in study sections, and review administrators will increase their efforts to identify and recruit minority members. The NIH will also continue to encourage the submission of nominations of minority reviewers by professional organizations and societies of minority scientists, while the NIH will monitor the membership of study sections to ensure the appropriate inclusion of scientists with expertise in health disparities.

Public Information and Community Outreach

Communicating research findings and health messages to all segments of the population is an integral part of NIH's mission. Such efforts are an important means of helping to reduce and ultimately eliminate disparities in the health of racial and ethnic minorities. The general public, patients, health care providers, the media, scientists, and policymakers need to be aware and informed about the findings from medical research that can be applied to improving health. The NIH must continue its efforts to translate highly technical research advances into clear, culturally relevant explanations of the steps individuals can take to improve their health.

Information on scientific findings and technologies is disseminated to scientific and other health professionals through various avenues: scientific publications, workshops and symposia, scientific meetings, consensus development conferences, press releases, special physician education programs, and clinical alerts concerning immediate health and safety issues. Access to information about scientific articles, NIH research grants, clinical trials, and treatment is also provided through extensive electronic databases.

To reach and respond to the public, Congress, and the media, NIH employs information offices, clearinghouses, electronic databases, Internet-based information services, public education programs, publications and press releases, as well as direct responses by letter and telephone. These provide information regarding participation in research protocols; the best current information on disease prevention and health promotion, diagnosis, and treatment of specific diseases and disorders; information about ongoing research; and referrals to other sources of information.

The NIH has identified three objectives for enhancing communications and outreach related to the goal of reducing health disparities (see

Table 1). Examples of proposed initiatives in support of these objectives are described below and are summarized in Table 4.

Selected Examples of Public Information and Community Outreach by Objective

1. *Develop research-based information resources.*

The NIH will develop materials that are targeted to the needs of a wide variety of audiences based on information needs identified through research, focus groups, and community interactions.

NIH Hispanic Communications Initiative. Many Institutes and Centers are supporting the NIH Hispanic Communications Initiative. For example, curriculum supplements are being translated into Spanish and other languages, including Navajo, for use in adult education and predominantly minority schools. An Exercise Guide and five "Age Pages" will also be translated into Spanish. *Salud para su Corazón*, a project to improve cardiovascular health among Hispanics, has developed materials that can provide information for consumers, health-care workers, and others to bring heart-health interventions to many specific communities and groups.

Internet-based Information Resources.

Members of the public are taking responsibility for their health by becoming well-informed patients. Increasingly, they along with health professionals, are turning to the Internet for information, where there are already thousands of health-related Web sites, including many with inaccurate, out-of-date, or misleading information. NIH has developed and launched in 1998 the MEDLINEplus Web site that meets the public's interest in accurate, current, and understandable health information. This new resource provides access to a rich array of full-text consumer health information on major diseases and conditions highly relevant to the

Table 4
Selected Examples of NIH Public Information and Community Outreach Initiatives to Reduce and Ultimately Eliminate Health Disparities

1. *Develop research-based information resources.*

NIH Hispanic Communications Initiative
 Internet-based Information Resources
 Drug Abuse and Addiction
 Minority Participation in Clinical Trials
 Mental Health Clinical Trials
 Complementary and Alternative
 Medicine Trials
 Health Information National Trends Survey
 Population-based Prevention Research
 Clearinghouses
 Aging Research Data

2. *Communicate research-based information to increase public awareness.*

Minority Scientists Advisory Committee
 National Diabetes Education Program
 Environmental Justice: Partnerships for
 Communication
 Public Input/Policy on Genetic Research
 Toxicology and Environmental Health and
 HBCUs
 Minority Recruitment in Clinical Trials
 Mental Health
 Complementary/Alternative Medicine
 Clinical Trials
 Hearing Loss
 Arthritis and Rheumatic Diseases
 Use of Web-based Information
 Asian and Pacific Islander Project
 Hispanic Men and Drunk Driving
 Asthma
 Eliminating the Disparity in Back-Sleeping in
 African Americans
 Science for the Lay Public

3. *Transfer knowledge to health care providers.*

Urban Clinical Center and Tuberculosis Trials
 Physician Participation in Cancer Clinical
 Trials
 National Kidney Diseases Education
 Program
 Mental Illness
 Cancer
 The National Eye Health Education Program
 Behavioral and Social Sciences and
 Communications

specific concerns of minority and underserved populations.

Clinical Trials Database. In early 2000, NIH launched an important new trans-NIH initiative, the Clinical Trials database. When fully operational, Clinical Trials.Gov will be a comprehensive resource for patients, families, and members of the public, providing access to clinical trials funded by the Federal Government and by private industry. Both MEDLINEplus and Clinical Trials.Gov will undergo significant improvements and enhancements in coming years with the benefit of user feedback. Substantial outreach efforts are targeted to promote awareness and use of these important health resources by minority and underserved communities.

Drug Abuse and Addiction. The NIH, in order to disseminate research findings on drug abuse and addiction among minorities, will sponsor a national conference on drug abuse and addiction in diverse communities to develop a guide and Web site where such information will be available, provide training on conducting research among minority groups, and improve dissemination of research findings among minorities.

Recruitment of Minorities into Clinical Trials. A trans-NIH goal is to increase the participation of minorities in study populations in all categories of clinical research as a means of facilitating clinical research as well as increasing access to treatments and other interventions being tested in such studies. To encourage and coordinate such efforts, NIH will establish a committee to develop guidance for design, implementation, and evaluation of clinical trials that recruit minorities. Many ICs are undertaking efforts to enhance the recruitment of minorities into clinical trials, and a few are described below.

Minority Participation in Mental Health Clinical Trials. In addition, the NIH will expand its efforts to increase the participation of

minorities in mental health clinical trials, particularly in several nationwide studies of treatment effectiveness, by placing advertisements in minority publications and others with large minority readership, by developing recruitment kits, fact sheets, and videotapes to educate prospective participants, and by developing other advertising materials aimed at underrepresented populations.

Minority Recruitment in Complementary/Alternative Medicine Clinical Trials.

NIH will also establish academic or clinical partnerships to enhance minority accrual in clinical trials of complementary and alternative medicine in a culturally sensitive manner and to promote participation of minority scientists in research. Ideally, community partners will be enlisted in efforts to enhance minority recruitment. Such efforts might include talks with relevant audiences in the community and arranging working relationships and linkages between community groups and research organizations. Clinical investigators will be taught to employ culturally sensitive therapeutic approaches while using appropriate communication and education techniques applicable to “real-world” settings, such as rural clinics and urban health centers.

Health Information National Trends Survey. The biennial Health Information National Trends Survey (HINTS), the first longitudinal study of Americans’ access to and use of health information, will oversample minorities to identify how people seek and acquire information about cancer. The survey will provide clearer pictures of current and emerging trends in seeking and using information on cancer as well as preferences.

Population-based Prevention Research. A database will be developed by NIH to include all population-based prevention research and will allow users to identify relevant projects, particularly those addressing health disparities.

Clearinghouses. Clearinghouses supported by the NIH are valuable resources for information on health issues and publications of NIH research. NIH will undertake efforts to better publicize Clearinghouses in minority communities as well as develop materials for leaders and members of minority communities on nutrition for pregnant mothers, children, and teenagers and on reading and getting ready for school.

Aging Research Data. NIH will enhance the capacity of various centers, such as the National Archive on Computerized Data on Aging and the Research Centers on Minority Aging Research, to: collect and archive databases suitable for secondary data analyses on health disparities; distribute the data through media such as CD-ROMs, to facilitate analyses of linked administrative or sensitive (e.g., geographic specific) data; provide workshops and summer institutes to assist potential users, especially at non-research universities; and provide post-workshop assistance through 800 numbers and online help.

2. *Communicate research-based information to increase public awareness.*

The NIH will continue to use a variety of communications strategies and mechanisms to provide the public with research-based information. The NIH also will undertake new projects and expand efforts to convey research information more effectively to racial and ethnic minorities.

Minority Scientists Advisory Committee. The Minority Scientists Advisory Committee will serve as a conduit of outreach to minority communities, with new duties specifically including local and national outreach.

National Diabetes Education Program. The purpose of the National Diabetes Education Program is to prevent the onset of the disease, promote early diagnosis, and improve the treatment and health of those with diabetes. A partnership of the NIH, the CDC, and some 150

public and private partners, the program stresses participation by all minority groups. Its work will be expanded to increase awareness of type 2 diabetes, to understand the disease and its control, and to advance unified approaches to care among minorities, providers, insurance purchasers and payers, and policy makers.

Environmental Justice: Partnerships for Communication. The NIH will expand the Environmental Justice communications program, enabling communities to be involved in identifying and addressing environmental health risks. By making citizens partners with researchers and practitioners, it enables them to have a demonstrable role in identifying and defining problems and risks related to environmental hazards.

Public Input/Policy on Genetic Research. The NIH will involve diverse populations in the planning, design, and implementation of public policy on genetic research and the use of genetic information. The NIH will support workshops, conferences, and meetings to explore and explain genetic research of particular interest to defined groups and communities.

Toxicology and Environmental Health and HBCUs. The NIH will expand its activities with the Historically Black Colleges and Universities (HBCUs) to provide information about toxicology, environmental health, and hazardous waste. In addition, NIH will expand its Toxicology and Environmental Outreach to Minority Communities project beyond these institutions to include more minority and disadvantaged communities.

Hearing Loss. The NIH will expand the Wise Ears! campaign to increase public awareness of hearing loss caused by noise with a special outreach effort to Hispanic seasonal workers and others who work in environments with dangerous noise levels.

Arthritis and Rheumatic Diseases. The NIH Health Partnership Program will continue to work with African Americans in Washington, D.C., to

address research and treatment needs and opportunities in arthritis and other rheumatic diseases among this group. A national program will ultimately cover the full range of minorities and the diseases of bones, muscles, joints, and skin that disproportionately affect them.

Delivery of Web-based Information. New efforts will be undertaken to facilitate use of web-based information by racial and ethnic minorities through the development of easy-to-use access and delivery mechanisms that promote the public's understanding of health information resources and are sensitive to cultural diversity issues, educational level, and language (e.g., Spanish). For example, support will be provided for a project to determine whether a diverse population of minority children and adolescents with type 1 diabetes, if given access to electronic information resources, will better manage their diabetes and avoid costly and debilitating complications. In another arena, NIH will provide technical consultation for the use of smart-card technology to improve both diabetes care and adherence to preventive measures in type 2 diabetic Latino and African Americans living in low-income Los Angeles County health districts.

Asian and Pacific Islander Project. This project builds upon the National Asian/Pacific Islander Cardiovascular Health Strategy Workshop held in May 1999, which established a set of priorities for a national research agenda, community outreach strategies, and community-based services in this targeted population. It is currently in the developmental phase of its community awareness campaign to promote heart-healthy behaviors. Planned activities include establishing a network of community partners to disseminate the messages and materials, developing culturally appropriate products and materials, establishing partnerships with local community groups, churches, clinics, and social service agencies, and other nontraditional organizations and groups, and developing and sustaining web-based activities.

Hispanic Men and Drunk Driving. The NIH will establish a partnership with the National Highway Traffic Safety Administration and Mothers Against Drunk Driving for a Drunk Driving Awareness campaign for Hispanic men. In cooperation with national advocacy organizations with expertise in Hispanic affairs or problems of drunk driving, the partners will research and develop a public awareness campaign, which will try to reach the target audience with important information.

Asthma. For a decade, the National Asthma Education and Prevention Program—Asthma Coalition Network has been helping to reduce disparities in diagnosis, treatment, morbidity, mortality, and preventive care for people suffering from asthma. Current projects focus on the poor, minorities, and children at high risk. Planned activities include funding additional coalitions and model programs that may be transferred to other communities, enlarging the partnership network for better dissemination of information and implementation of asthma interventions, and expanding opportunities for continuing education and distance learning on the Web.

Eliminating the Disparity in Back-Sleeping in African Americans. The NIH is expanding its intensive campaign with the African American community to place babies on their backs to sleep, in addition to supporting related research and evaluation activities. While significant progress has already been made in this effort, the ultimate goal is to completely eliminate the disparity in back-sleeping (and, ultimately, the SIDS rates) within the next three years.

Science for the Lay Public. NIH will help in supporting Science for the Lay Public Forums, in cooperation with the General Clinical Research Centers and the Research Careers in Minority Institutions-Clinical Research Centers. This effort will include meetings on health disparities in predominantly minority community centers, churches, and schools. Investigators and administrators will be encouraged to work locally

to recruit more minorities in clinical research studies.

3. *Transfer knowledge to health care providers.*

Educating health care providers about research findings and disseminating science-based health messages is a critical link in NIH's efforts to reduce health disparities. The NIH will continue to develop partnerships with health care providers to help ensure that NIH's health messages reach various racial/ethnic populations.

Urban Clinical Center & Tuberculosis

Trials. The NIH will increase support of an Urban Clinical Trials Center to provide health-care providers in the Washington, D.C. area greater access to tuberculosis clinical trials.

Physician Participation in Cancer Clinical

Trials. The NIH will continue to encourage participation in cancer clinical trials by physicians who are members of health plans. NIH has established partnerships with several health plans as well as physician practice groups which had not been active in cancer clinical trials. This partnership, called the *Expanded Participation Project* (EPP), has developed a menu of protocols as well as informatics to facilitate patient accrual and data collection. Howard University is currently a member of the EPP. The EPP will be extended to another historically African American institution, Meharry Medical College.

National Kidney Diseases Education

Program. The NIH will establish a National Kidney Diseases Education Program to reduce the burdens of end-stage renal disease on minorities and to work with patients and professionals to identify the most effective screening and disease interventions, with appropriate messages to specific audiences.

Mental Illness. The NIH Constituency Outreach and Education Program will be

continued and broadened, with outreach partners in all States, the District of Columbia, and Puerto Rico. The partners will focus on racial and ethnic minorities and use various means to educate the public about mental illness and its treatment. To help close the gap between research and services, partners will stress the importance of the professional's understanding of the patient's culture.

Cancer. To understand how best to use dissemination of information to reduce health disparities in cancer, the NIH, the American Cancer Society, and the CDC will form a partnership focusing on needs, review of interventions, resource evaluation, and priorities in particular communities or among particular groups. To the same end, the NIH will establish partnerships with local and regional health organizations.

The National Eye Health Education

Program. This Program comprises more than 50 public and private partner organizations engaged in increasing public and professional education on scientifically based health information that can help to preserve sight and prevent blindness. Because of the high incidence of glaucoma, diabetic retinopathy, and visual impairment in minority populations, informational and educational materials are tailored to meet the needs of those target audiences. This includes the development of Spanish language materials, such as the diabetic eye disease program *Ojocon su Visión* (Watch Out for Your Vision), where it is determined that it would help disseminate an important public health message.

Behavioral and Social Sciences and

Communications. Critical to the mission of NIH is ensuring that research findings and health messages are clearly communicated to all segments of the public. NIH health messages are a powerful tool for diminishing health disparities through education. The NIH will examine how the techniques and strategies from the behavioral and social sciences could be applied in evaluating and improving health

communications targeted to various racial/ethnic populations.

Conclusion

This document describes an ambitious plan being undertaken by NIH for reducing and ultimately eliminating health disparities among racial and ethnic minorities. Creation of a Trans-NIH Working Group on Health Disparities, comprised of the most senior leaders at the NIH and their development of this plan are indicative of our continued commitment to supporting efforts directed to improving human health, including among racial and ethnic minorities. This effort cuts across disease areas and organizational boundaries and involves a trans-agency commitment. It augments the efforts of each Institute, Center, and program office in the Office of the Director, NIH in this important arena. As in many areas of research, more remains to be done. The medical research community working with, and informed by, the public, patients, health care providers, policymakers, and others has and will continue to develop new knowledge that leads to improvements in the prevention, diagnosis, and treatment of diseases and disabilities that contribute to health disparities.

In Fiscal Year 2000, the NIH is spending over \$1.3 billion on research; research infrastructure; and public information and community outreach efforts to reduce health disparities. This provides a strong base for further investments over the longer term—investments that promise substantial gains in reducing the incidence, prevalence, severity, and social and economic burdens of diseases and disabilities that affect racial and ethnic minority populations.

Appendix

Institute, Center, and OD Program Office Abbreviations and Web Site Addresses

NIH	National Institutes of Health http://www.nih.gov/
Addressing Health Disparities: The NIH Program of Action http://healthdisparities.nih.gov	
NCI	National Cancer Institute http://www.nci.nih.gov/
NEI	National Eye Institute http://www.nei.nih.gov/
NHLBI	National Heart, Lung, and Blood Institute http://www.nhlbi.nih.gov/
NHGRI	National Human Genome Research Institute http://www.nhgri.nih.gov/
NIA	National Institute on Aging http://www.nih.gov/nia/
NIAAA	National Institute on Alcohol Abuse and Alcoholism http://www.niaaa.nih.gov/
NIAID	National Institute of Allergy and Infectious Diseases http://www.niaid.nih.gov/
NIAMS	National Institute of Arthritis and Musculoskeletal and Skin Diseases http://www.nih.gov/niams/
NICHD	National Institute of Child Health and Human Development http://www.nichd.nih.gov/
NIDCD	National Institute on Deafness and Other Communication Disorders http://www.nih.gov/nidcd/
NIDCR	National Institute of Dental and Craniofacial Research http://www.nidcr.nih.gov/
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases http://www.niddk.nih.gov/
NIDA	National Institute on Drug Abuse http://www.nida.nih.gov/
NIEHS	National Institute of Environmental Health Sciences http://www.niehs.nih.gov/
NIGMS	National Institute of General Medical Sciences http://www.nigms.nih.gov/
NIMH	National Institute of Mental Health http://www.nimh.nih.gov/
NINDS	National Institute of Neurological Disorders and Stroke http://www.ninds.nih.gov/
NINR	National Institute of Nursing Research http://www.nih.gov/ninr/
NLM	National Library of Medicine http://www.nlm.nih.gov/
CC	Warren Grant Magnuson Clinical Center

<http://www.cc.nih.gov/>

NCCAM National Center for Complementary and Alternative Medicine
<http://nccam.nih.gov/>

NCRR National Center for Research Resources
<http://www.ncrr.nih.gov/>

FIC Fogarty International Center
<http://www.nih.gov/fic/>

OAR Office of AIDS Research
<http://www.nih.gov/od/oar/index.htm/>

OBSSR Office of Behavioral and Social Sciences Research
<http://www1.od.nih.gov/obssr/obssr.htm/>

ODP Office of Disease Prevention
<http://odp.od.nih.gov/>

ORMH Office of Research on Minority Health
<http://www1.od.nih.gov/ORMH/main.html/>

ORWH Office of Research on Women's Health
<http://www4.od.nih.gov/orwh/>